

**FAMILIES HELPING FAMILIES:  
TAX RELIEF STRATEGIES FOR ELDER CARE**

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**HEARING**  
BEFORE THE  
**SPECIAL COMMITTEE ON AGING**  
**UNITED STATES SENATE**  
ONE HUNDRED EIGHTH CONGRESS  
SECOND SESSION

WASHINGTON, DC

FEBRUARY 10, 2004

**Serial No. 108-28**

Printed for the use of the Special Committee on Aging



U.S. GOVERNMENT PRINTING OFFICE

93-173 PDF

WASHINGTON : 2004

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## **FAMILIES HELPING FAMILIES: TAX RELIEF STRATEGIES FOR ELDER CARE**

**TUESDAY, FEBRUARY 10, 2004**

U.S. SENATE,  
SPECIAL COMMITTEE ON AGING,  
*Washington, DC.*

The committee met, pursuant to notice, at 10:10 a.m., in room SD-628, Dirksen Senate Office Building, Hon. Larry E. Craig (chairman of the committee) presiding.

Present: Senator Craig.

### **OPENING STATEMENT OF SENATOR LARRY E. CRAIG, CHAIRMAN**

The CHAIRMAN. Good morning, everyone. The U.S. Senate Special Committee on Aging will be convened. I apologize for my tardiness, but I was over-booked this morning, or I should say double-booked. I do pride myself starting hearings on time, but I was trying to help figure out if we can pass a national energy policy this year.

So, again, let me welcome all of you. I would like to thank our witnesses for joining us today on a growing issue of national importance, the issue of family caregiving. Today's hearing will highlight the stress and financial challenges faced by family caregivers of aging and vulnerable relatives, and shine a light on tax relief strategies for relieving the financial burdens freely undertaken by many adult children.

Over the past few years, the Aging Committee has held several hearings on different facets of the growing long-term care crisis in our country. A major concern of mine is that the Federal long-term care policy mix may not have the right incentives, especially when it comes to the tough choices faced by families who want to care for their aging and vulnerable relatives.

One extraordinary strength of our long-term care system is that families, not government, provide 80 percent of the long-term care for older persons in the United States. That is a phenomenal figure. It speaks well for our people.

The U.S. Administration on Aging reports that about 22 million people serve as informal caregivers for seniors, with at least one limitation on their activities of daily living. These caregivers often face extreme stress and financial burden, especially those that we call the sandwich generation. Sandwich generation, many of you know—you have heard the term—refers to those sandwiched between caring for their aging parents and caring for their own children. It is difficult for families to balance caring for children and



saving or paying for college, while at the same time struggling with financing care for their aging parents.

For many families, the nursing home is the only solution for providing long-term care, and that can be a good choice. For other families, keeping aging or vulnerable relatives in their own home or in the caregiver's home makes sense. That is why I am interested in promoting tax relief strategies for families who face high stress and financial expenses as they care for their aging and vulnerable parents outside institutional arrangements.

Tax relief strategies should not preclude seniors or those near retirement from purchasing long-term care insurance. Certainly, the package that we are now working on that was provided in the Medicare prescription drug bill and a variety of alternatives could well, through health savings accounts, allow the financing of long-term health care. We hope it becomes something that all families and individuals look at as a reasonable and responsible option.

Tax relief for families' caregiving expenses should be provided for high-risk seniors who cannot qualify for long-term care insurance policies. This is a national issue requiring a flexible national response to ensure seniors and their families have high-quality choices. This hearing will help guide the Congress in designing the right policy mix, I hope.

With that preface, let me say how pleased I am once again to welcome all of you to our hearing today. I look forward to your testimony. We are going to treat you all as one panel, and so we will ask that all of you give your testimony and then I will ask questions, and some of those will be the types of questions that all of you might want to respond to.

So with that, let me ask our first panelist, Trudy Elliott—I guess I would call her a true expert on this issue. Trudy is a family caregiver and home health care nurse from my State of Idaho, living in the north end of our State.

So, Trudy, welcome to the committee. Why don't you proceed? Thank you.

**STATEMENT OF TRUDY ELLIOTT, FAMILY CAREGIVER AND  
HOME HEALTH NURSE, COER D'ALENE, ID**

Ms. ELLIOTT. Thank you, Senator Craig. I would like to thank the committee and Senator Craig for inviting me to come and tell my story.

When I was contacted, my thought was this is a story that needs to be told and the fact that it is not a unique story. My hope at the conclusion of my testimony today is that you will visualize a different future for our senior population, as well as for the family caregivers, through the congressional movement which you have suggested, and recognizing not only the emotional strain, but as well as far as the financial strain which is occurring.

How do I possibly convey the feelings that I have had in the last 4 years, feelings of frustration, concern, honor, with a lot of the multiple fragmented thoughts that have gone through my head as I am sitting in different arenas with my parents and my sister as well?



My first challenge of my middle years, which is an interesting concept to sit here and talk about my middle years—I am not sure what that means.

The CHAIRMAN. They are really quite comfortable.

Ms. ELLIOTT. I am getting quite used to them.

Where do I start? Imagine being at a family dinner with your mother and father, whom you have seen very frequently, and having your father pull you aside and say, “I need help. What am I going to do? There is something wrong with your mother.” I am looking at him going like what? He said, “well, she can’t write, she can’t drive her car. I don’t know what I am going to do. She is up all night. I can’t get any sleep.”

The promise that they made together was that they would never, ever put each other in a nursing home, which isn’t a bad thing, but many of that generation promised that they would be together forever. In the 50 years that they had been married, I think maybe they had spent 2 to 3 days apart. One of those was to be with me when my third child was born. So you can see that the impact on these 70- and 80-year-old people would be more than just an illness.

They had both been very modest all of their lives, hard-working people, had saved money and had never wanted to be a burden to anyone. So they put away their wonderful retirement nest that they would get to enjoy. About the time that they were able to enjoy that, my mother developed Parkinsonism with a Lewy body dementia, which was a very rapidly progressing illness that took her from being an active Assessor of Garfield County to a person who needed total care.

In this time, my father was attempting to be a caregiver, a role which he had not been trained to because my mother had been the caregiver all of their married lives. So there was a real transition for our whole family. Since that day, probably 4 or 5 years ago, I have been with my mother and my father in multiple arenas, in and out of the hospital, in and out of the skilled nursing facility, finally with the last part of her life in an assisted living facility, small assisted living facility, which was able to care for her up until the day she died, along with my supervision.

Part of my role with my parents seems to be their advocate, and I feel that that is a role that I am even playing today being here in this hearing. My mother lost her ability to speak, and it is interesting that when people lose their ability to speak, people also think that they have lost their ability to say what it is that they want and what they don’t want.

So my role with my mother was to be her advocate in these arenas to make sure that her needs were met, which she had defined to me years ago in her advance directive. Her care initially started in our home and then progressed to these, and because of my parents living with very modest means we were having to pay for the caregiver out of their retirement nest. I don’t think anybody has any concept of how rapidly that will disappear.

Because of my mom’s illness, also it took away the ability of my parents to care for themselves in their home and I found myself having to pull on the resources that I had learned throughout my life in working as a home care nurse. Many times, people would



ask me why I wanted to play that part? I can't imagine not. My parents were there for me. I can't imagine not playing that role, even though it was a very difficult role to play.

My second challenge of my middle years was the fact that my sister was diagnosed with metastatic cancer during this time when my mother was also ill. Even though it wasn't the sandwich generation, we experienced what the impact of her care was on her son, who was 39.

I am sorry. That is still a fairly emotional time period for me.

How far can one person be spread? Much further than you can ever imagine. Actually, after a continued fight to be a survivor, my sister died in our home, which was an honor for all of us. Our family had been presented also for my mother's final journey, which had occurred approximately 10 days before my sister had died in our home. What an honor for me to be there for two very important people in my life.

The third challenge of my middle years was my father, who is now 82 years old, and it is an ongoing thing that we are incurring with him today as far as his care environment. I am sure that this Act that is being suggested will be very much a financial relief for families such as myself who have experienced the sandwich generation.

Thank you.

[The prepared statement of Ms. Elliott follows:]



My Journey into the Sandwich Generation  
Trudy Elliott  
February 10, 2004

My hope at the conclusion of my testimony is that you will visualize a different future for our senior population as well as family caregivers through the congressional movement in recognizing not only the emotional stress as well as the financial strain that is facing us today.

How do I possibly convey the feelings, emotions, frustrations, guilt, financial concerns along with multiple fragmented thoughts that have flowed through my mind as a primary caregiver for the last four years in my testimony to you today?

**First Challenge of My Middle Years**

Where do I start? Imagine being at your parents' home for a holiday dinner and having your father say to you, "What am I going to do about your Mom? Something is really wrong and I need your help?" He began to paint a picture of someone I didn't recognize by explaining that she can no longer write her name, drive the car safely, nor prepare a meal. My Dad continued to tell the story which described a typical day and several never-ending nights with my Mom who was not sleeping or able to do her own personal care. As he looks at me with tears in his eyes, he decides that he is going to have to place her in a nursing home, which is something that both of them had promised each other would never happen. Mom and Dad had been married for over fifty years and had never spent more than two or three days apart. They both had also worked all of their lives so that they would have a good retirement "nest egg" to live on and not be a "burden to their children."

Since that day at my parent's home over four years ago, I have spent countless hours playing the part of the family caregiver starting with my caring for my mother in our home alternating with various admissions to the hospital, skilled nursing facilities, and an eventual placement in an assisted living facility due to her rapidly developing neurological disease of Parkinsonism with Lewy Body Dementia.

Because of Mom's disease process taken away her ability to speak, I felt it essential to be with for as many hours as possible to serve as her advocate. Each time that I was placed in this role of primary caregiver I was so grateful that I had a baseline working knowledge of the medical system and how to access the resources that were available in our community. Many times I would find myself wondering how the caregivers that had no knowledge of the available resources were surviving, not only emotionally, but financially as well. Many times people would ask me why I would want to play such an active role in my parent's care. The answer is I can't imagine not doing it! My parents did not ever hesitate to be a supportive presence in my life, so did I not have a responsibility to do the same for them?



My mother's care needs continued to escalate which made it impossible for me to provide her twenty four hour care as well as working full time in a fifty to sixty hour a week job as a Director for a Home Care Agency, full time mother of three with two living at home, full time spouse, and a resource for my Dad. During the time that my mother was being cared for in our home, we had to hire a private caregiver which was costing anywhere from eighty to ninety dollars a day. This financial outlay was paid for by my spouse and me since there was no funding available either through Medicare or Medicaid. We were fortunate that we had the resources to do this on a short term basis, because many families are not able to budget for this responsibility. Our family was certainly not in a position that I could give up my employment to care for my mother on a full time basis.

#### **Second Challenge of My Middle Years**

During the time of my mother's progressive illness, my sister was diagnosed with terminal metastatic cancer which required extensive surgery, chemotherapy, and radiation treatment. I would travel to care for her after her surgeries and multiple treatments, which created an extreme emotional pull since I knew that I needed to truly be in five to six places at the same time. Not only did I still need to be very present in my job, but my children, mother, husband, and father also needed a part of me. How far can one person be spread? Much further than you can imagine, actually. After a continued fight to be a survivor, my sister died at our home in March just ten days after my mother's death. All of our family, including her son and my father was able to be with her for her final journey. Our family had been present at my mother's final journey just ten days prior to my sisters. What an honor for me to be there for two very important people in my life.

#### **Third Challenge of My Middle Years**

Until approximately one year ago my Dad, who just turned 82, had been living in the home that he shared with my Mom for over fifty years "because this is where the memories are." With my Mom no longer close enough for him to reach out to; He continued to decline not only in health, but in his spirit as well. My husband and I purchased a mobile home for him in our home town so that I would not have to travel for over three hours each way to care for him. Within two weeks of arriving, he was hospitalized and remained within the medical environment of the hospital, transferred to a skilled nursing facility and eventually transferring to the same assisted living facility where my Mom was located. He remained in this facility until after my Mom died on March 3<sup>rd</sup> of last year. Just recently he was able to return to his new mobile home and is incredibly happy to be in his own space. I visit him almost daily: grocery shopping; transporting him to his medical care; acting as his Power Of Attorney; maintain his living space; buy his clothing-----and the list goes on. Many people ask why I just don't hire someone to do these things for him and decrease my stress. Two words would describe the reasons---love and responsibility. My Dad is also on an extremely limited budget with his care needs costing over \$15,000 since last September not counting his prescriptions which cost approximately \$900.00 a month. If he needed to return to an assisted living facility in the future he would be paying over \$3500 a month. Currently he is receiving less than \$700.00 a month from social security and does not qualify for any



other assistance. He will very quickly outliving the money that he and my mother put aside for their “dream years.” Currently there is no provision for our family or my father to pay for any of these expenses which allow him to remain in his home or ours.

Families of today are at a critical point with the demands being placed on the Sandwich and Club Sandwich Generation. My hope for the future is to see the creation of a tax credit that would provide a financial buffer to not only the senior population but the sandwich generation that supports them.

It was an honor to participate in both my mothers and sister’s final journey. My family and I in our role of family caregivers will continue to provide my father with the love, security and peace of mind he so genuinely deserves.



The CHAIRMAN. Trudy, thank you. That is tremendously powerful testimony, and I think you said it well at the beginning, reflective not just of your experience, but thousands like you across the country who feel that responsibility and love to do what you have done. Thank you.

Now, let us move to Sandy Markwood. Sandy is President and CEO of the National Association of Area Agencies on Aging. Sandy, welcome to the committee.

**STATEMENT OF SANDY MARKWOOD, CHIEF EXECUTIVE OFFICER, NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING, WASHINGTON, DC**

Ms. MARKWOOD. Thank you so much for having me. Good morning, Chairman Craig. My name is Sandy Markwood. I am the Chief Executive Officer of the National Association of Area Agencies on Aging, and I really want to thank you for inviting me here today to talk about family caregiving.

I am pleased to be here today to represent the Nation's area agencies on aging, and also the Title VI Native American aging programs, whose fundamental mission is to support people to live in their homes and in their communities with dignity for as long as possible.

The 655 area agencies on aging and the 232 Title VI aging programs are dedicated to enhancing the quality of life of older Americans and providing support to their families. In this way, they provide supportive services and a whole range of preventive services. They are the single point of entry and information for older adults and their caregivers to find out about the range of community-based services that exist to support older adults and their caregivers.

These services include congregate meals, in-home meals. They also include personal care, chore services, the nursing home ombudsman program, transportation, and senior centers. But critically, since the reauthorization of the Older Americans Act in 2000, it also includes a whole range of family support for caregivers. Through working with caregivers, we know that family caregivers are the heart of the long-term care system in this country, and they are also the backbone of it.

Uncompensated care by family members makes it possible for millions of older adults with long-term care needs to avoid costly and often unnecessary and unwelcome placement in formal care settings. Recent estimates have valued the services provided by family caregivers at \$257 billion a year. That is an astounding figure.

Caregiving, however, also has a cost to the caregiver, though many would not want to admit it. Numerous studies have shown that caregiving exacts a great financial, emotional and physical toll on caregivers. Many caregivers forgo job advancements, reduce their hours on the job, cut back to part-time, take temporary or extensive leaves of absence to be able to stay home to care for family members. These actions result in lost compensation, diminished contributions to employee-sponsored pension programs, as well as limitations on employee benefits. Additionally, caregivers often de-



plete their own family personal savings to be able to try to compensate for that loss of income.

Caregiving also has associated costs. As Trudy mentioned, direct expenses incurred by family caregivers include the purchase of prescription drugs, durable medical equipment, home modifications, and physical therapy for the care recipient. These all have a cost. It is a cost that caregivers welcome to pay, but sometimes it adds up.

There is no doubt that caregivers, many of whom are raising children, working full- or part-time and are facing challenges of aging themselves, are stressed with multiple responsibilities and they need help. It is only right that those that give help should receive help.

Congress took the first steps in recognizing both the tremendous contributions of family caregivers and the need to provide them with some critical relief by including the National Family Caregiver Support Program in the reauthorization of the Older Americans Act in 2000.

This program provides critically needed assistance to families as they struggle to provide help to loved ones. It builds upon services that already exist in the community through the Older Americans Act, but it expands on it and provides value-added services for caregivers.

In the 4 years since its establishment, appropriations for this program have gone from \$125 to \$129 million. While we appreciate the yearly increases, given the vast numbers of family caregivers and the extent of the need, I would be remiss in my role as an advocate if I didn't draw attention to the fact that the program still is underfunded.

These dollars, though they are augmented by the State and local level, are stretched thin. AAAs report that they work very hard to be able to provide the needed services. The most used service is respite care, and that is also the most expensive service. Respite has been able to provide proven care to alleviate, at least temporarily, some of the physical and emotional stresses related to caregiving. It also helps to delay expensive institutionalization. However, because of the cost, caregivers often need more respite than they can afford privately, and they also need more respite than AAAs are able to provide with competing service needs and limited funding.

Additional services provided by AAAs in Title VI aging programs under the National Family Caregiver Support Program include supportive and supplemental services, such home modification, transportation and chore services. Given the flexibility of this program, what area agencies have been able to do is to provide small sums of money to caregivers to be able to help them get chore services, personal care, even to get assistance in mowing the lawn. These small services can make the difference between the exhaustion level of a caregiver and their ability to be able to keep somebody in their home or reaching a crisis level where they feel like they need institutionalization.

In saying this, what we found out through this program, and thousands of examples of wonderful services provided at the community level, is that the needs of caregivers are unique, but they



all have needs and they all need assistance. They need emotional assistance, they need physical assistance, and they need financial assistance.

Caregivers truly are the heart of the long-term care system and we as a Nation must do more to address the emotional, physical and financial challenges associated with caregiving. The National Family Caregivers Support Program was a significant first step in providing some relief and support to caregivers, and we look forward to working with you and your committed staff to ensure that the passage of the SECURE Act takes a further step forward toward providing needed financial relief to this selfless population.

[The prepared statement of Ms. Markwood follows:]



*Statement of*

**SANDRA MARKWOOD**  
Chief Executive Officer  
The National Association of Area Agencies on Aging

**Before the  
Senate Special Committee on Aging**

**Hearing on  
Families Helping Families: Tax Relief  
Strategies for Eldercare**

February 10, 2004  
628 Dirksen Senate Office Building  
Washington, DC 20510



Good morning, Chairman Craig and distinguished members of the Special Committee on Aging. My name is Sandy Markwood, and I am the Chief Executive Officer of the National Association of Area Agencies on Aging (n4a). Thank you, Senator Craig, for inviting me to testify on the important issue of family caregivers.

Family caregivers truly are the heart of long term care and n4a believes strongly that legislation that supports the selfless, dedicated work of our nation's more than 23 million caregivers, whether it provides financial, physical or emotional relief, will make a positive difference in the lives of both the caregivers and those they love and as such should be implemented as soon as possible. The SECURE Act legislation you will offer, which provides a targeted caregiver tax credit, will help alleviate some of the tremendous financial burdens that millions of families face in providing care for loved ones who are no longer able to fully care for themselves. n4a stands ready to work with you toward the swift implementation of a targeted caregiver tax credit bill that will provide needed relief to our nation's caregivers.

**The Mission of N4A and AAAs**

As the Administration recognized in its' FY 05 Budget Proposal, not only are home and community based services the overwhelming preference of individuals with long term care needs, but these services are also the most cost effective means of providing long term care services. I am pleased to be here today on behalf of our nation's Area Agencies on Aging (AAAs) and Title VI Native American aging programs whose fundamental mission is to help older Americans stay in their own homes and



communities with maximum dignity and independence for as long as possible. The 655 AAAs and 232 Title VI aging programs are dedicated to enhancing the quality of life for older Americans and their families by providing information about and access to a variety of aging supportive and preventative services in every community in the nation. AAAs and Title VI programs often serve as a "single point of information" for the complex and fragmented range of home and community-based services for older adults and their caregivers. These services include congregate and home-delivered meals, other in-home services (including personal care and chore services) for the frail elderly, elder abuse prevention and protections, the nursing home ombudsman program, senior centers, transportation, consumer information, education and counseling and senior employment and a broad array of caregiver services.

For over 35 years, AAAs and Title VI aging programs have effectively and efficiently served populations across the country that are geographically, racially, culturally and ethnically diverse and found innovative ways to meet the needs of millions of older adults. These agencies offer programs that make a difference in the lives of all older adults ... from the frail older person who can remain at home if they receive the appropriate services to those who are healthy and can benefit from the activities and socialization provided by community-based programs such as senior centers. And, AAAs also play a critical role in supporting our nation's often unsung heroes—family caregivers.



**The Toll of Caregiving on Caregivers**

Not only are family caregivers the heart of the long term care system in this country, they are also the **back bone** of long term care. Uncompensated care by family members makes it possible for millions of older adults with long term care needs to avoid costly and often unnecessary and unwelcome placements in formal care settings. Recent estimates have valued the services provided by family caregivers at \$257 billion annually (Arno, "Economic Value of Informal Caregiving"). Caregiving, however, has a cost to the caregiver—though many would never want to admit it. Numerous studies have shown that caregiving exacts a great financial, emotional and physical toll on the caregiver.

Many caregivers forego job advancements, reduce their hours on the job, cut back to part-time, or take temporary or extended leaves of absence to stay at home to care for family members. These actions result in lost compensation, diminished contributions to employer sponsored pension plans and limitations on other employee benefits. Additionally, caregiver's often deplete their own personal savings as they try to compensate for lost wages and employee benefits.

Reduced wages and job insecurity also negatively affects caregiver's retirement security. This is a particular problem for women who constitute the majority of this nation's caregivers. In a caregiver survey conducted by the MetLife Mature Market Institute, respondents reported an average lifetime earnings loss of over \$550,00 as a result of their caregiving responsibilities—and this figure jumps to \$659,000 when



pensions and Social Security are taken into account. Women, in general, face greater retirement insecurity since their earnings tend to be lower than those of men and many women take time out of the workforce to raise children.

Caregiving itself has associated costs. Direct expenses incurred by family caregivers themselves often include the purchase of prescription drugs, durable medical equipment, home modifications and physical therapy for the care recipient. A 1998 study by the National Alliance for Caregiving found that almost half (49%) of caregivers surveyed suffered "financial hardship" directly related to their caregiving. The Millbank Quarterly reports that families taking care of a relative with a chronic condition spend two and a half times more for out-of-pocket medical expenses.

In addition to the financial toll, caregiving also takes an emotional and physical toll on the caregiver. Caregivers cite an increased prevalence of depression, stress, anxiety, frustration and feelings of being overwhelmed than the general public. The American Journal of Public Health reported that a four-year study of middle-aged and older caregivers found that middle-age and older women caring for a relative were almost six times as likely to suffer depression or anxiety. Depression increases the risk of heart disease, cancer, diabetes and other chronic conditions, other negative health effects experienced by caregivers at a higher than normal prevalence. (According to the American Journal of Preventive Medicine last year), include high blood pressure, poorer immune function, sleeplessness and an increased risk of mortality. All of these health risk factors have a cost associated with them as well.



Caregiving can also cause chronic and acute physical strain on the caregiver—many of whom are aging themselves. A study by the American Society on Aging found that while the average age of a caregiver is 57, over one third of caregivers are 65 years old or older. Caregiving activities such as helping the care recipient out of bed, bathing or changing clothes can, if done improperly, can and often do cause injuries that leave the caregiver unable to provide care, and in some cases, in need of care themselves.

Reports have indicated that the stress associated with caregiving, especially over a prolonged period of time, negatively affects a caregiver's immune system, making them more susceptible to illness. Often times a caregiver will ignore their own symptoms until an acute condition arises.

Population trends forecast a greater need for family caregivers in the near future as baby boomers age. Thanks to advances in health care and medical technology, life expectancy has increased, and many persons can expect to live to be over 77 years old. However, with these longer lives often comes the increased need for long-term care. Currently individuals age 85 and above constitute one of the most rapidly rising populations in the country and it is this population that is in poorer health, has more chronic diseases and functions least independently overall. Studies show that due to lower birth rates, higher divorce rates, and low savings rates, baby boomers are not planning for their later years and will likely face great caregiver challenges.



There is no doubt that caregivers, many who are also raising children, working full or part-time or are facing the challenges of aging themselves, are stressed with multiple responsibilities and need help. It is only right that **those that give help should receive help too.**

#### **The National Family Caregiver Support Program**

Congress took the first steps in recognizing both the tremendous contributions of family caregivers, and the need to provide them with some critical relief, by including the National Family Caregiver Support Program (NFCSP) in the reauthorization of the Older Americans Act in 2000. This program provides critically needed assistance to families as they struggle to provide help to loved ones. It builds upon services provided under the OAA in local communities throughout the country. In the four year's since its establishment, appropriations for the Program increased from \$125 to the current level of \$159 million. While we appreciate the yearly increases, given the vast numbers of family caregivers and the extent of their need, I would be remiss in my role as an advocate if I did not draw attention to the fact that this program remains woefully under funded.

These dollars, though augmented at the state and local level, are stretched thin. AAAs report that the most sought after service provided under the NFCSP -- respite care -- is also the most expensive. Respite care has proven to alleviate, at least temporarily, some of the physical and emotional stresses related to caregiving, reducing the risk of abuse or neglect, reducing strained relationships between caregiver and care recipient,



and extending the delay of institutionalization of the care recipient. However, because of its costs, caregivers often need more respite than they can afford privately or that AAAs, who struggle with competing service needs and limited funding, have the capacity to provide. Attached to this testimony is one poignant example of the value of respite care to a caregiver. (Attachment A)

Additional services provided by AAAs and Title VI aging programs under the National Family Caregiver Support Program include supportive and supplemental services such as home modifications, transportation, and chore services. Given the flexibility of the NFCSP, AAAs and Title VI programs have developed truly novel and very effective programs targeted to meet the individual needs of caregivers. What our members have found is that sometimes caregivers who are stretched to the limit can benefit tremendously from occasional help with shopping, house cleaning or lawn maintenance. Sometimes a small stipend to help caregivers get assistance to cover these chores will give them the extra time and energy they need to provide unstressed care to their loved one.

Through the Eldercare Locator, the national toll free telephone information and referral which n4a, along with the National Association of State Units on Aging, administers through a grant from the Administration on Aging, we have learned that caregivers often reach out when they are in a crisis. This is a time when they may consider placing their loved one in an institutional facility when all they really need is access to one or two supportive services to be able to keep caring for them at home. The Eldercare Locator



has successfully helped over a million older adults and their caregivers get connected to needed services in communities across the nation.

Through the NFCSP, AAAs and Title VI agencies are successfully providing services and support to thousands of caregivers nationwide. An n4a survey done in December, 2001 lists almost 300 examples of how this program has begun to provide critical support and relief for caregivers across the country. Some innovative examples of AAA and Title VI NFCSP funded efforts include:

- In Georgia, AAAs pulled a portion of their NFCSP funding to produce a magazine targeted to inform the public about caregiving issues and the resources that exist in each AAA in the state to assist caregivers. Produced quarterly, the magazine has helped caregivers learn critical information about their caregiver roles and the community services available to help them.
- Through the n4a/Administration on Aging NFCSP program *Making the Link*, nearly 200 AAAs are working with physicians, nurses and discharge planners to help identify caregivers and connect them to support services in the community.
- The Hawkeye Valley (IA) AAA offers a Caregiver Helpline and Case Management Services to help caregivers find and manage the services that their care recipient needs.
- The Area II AAA in Lewiston (ID) offers the LINKAGE program in which caregiver peers provide support to one another.
- An AAA in Indiana is coordinating with the local hospice, libraries, parish nurses and community legal services to provide caregiver workshops



What the AAA and Title VI agencies have learned through their experience in implementing the NFCSP is that the needs of caregivers are varied and unique but all caregivers need assistance. And, **ANY** financial assistance that caregivers can get is beneficial and can make a major difference in their lives as well as their ability to care for their loved ones. The Assistant Secretary on Aging reported last September that of the 23 million caregivers nationwide, 85% are receiving no outside help. Many caregivers have limited resources, with approximately half of all caregivers having a household income of less than \$35,000 (Kaiser Family Foundation, 2001), and many caregivers are living on fixed incomes. **The bottom line is that caregivers need financial relief.**

#### **Conclusion**

Caregivers are truly the heart of the long term care system and we, as a nation, must do more to address the emotional, physical and financial challenges associated with caregiving. The National Family Caregiver Support Program was a significant first step in providing some relief and support to caregivers and we look forward to working with you and your committed staff to ensure that the passage of the SECURE Act takes a further step forward toward providing financial relief to this selfless population.



The CHAIRMAN. Well, Sandy, thank you very much. I think you have broadened the scope of the picture of this issue very effectively and I appreciate that for the hearing record.

Now, let us turn to Gail Hunt. Gail is President and CEO of the National Alliance for Caregiving. Gail, welcome to the committee.

**STATEMENT OF GAIL GIBSON HUNT, PRESIDENT AND CHIEF  
EXECUTIVE OFFICER, NATIONAL ALLIANCE FOR  
CAREGIVING, BETHESDA, MD**

Ms. HUNT. Thank you, Senator Craig, for the opportunity to provide information on family caregiving. In light of your interest in helping older people to stay in the community and help caregivers in their effort to continue caring for relatives and friends as long as possible, I thought I would focus on some of the latest data on caregiving. Who are the family caregivers and what do we know about them, and what impact does caregiving have on their lives?

First, some basic data on family caregivers. Nearly a quarter of U.S. households are involved in family caregiving. This number is important because it shows how involved family members are in caring for one another and how large an issue family caregiving is in our country. It is a myth that Americans abandon their older relatives to nursing homes. Approximately 80 percent of the care, as you mentioned, for older people is done by family and friends.

The profile of the family caregiver is a 46-year-old baby-boomer woman who is married and works and cares for her 77-year-old mother who lives nearby. The caregiver spends an average of more than 20 hours a week providing care, and caregiving typically lasts more than 4 years.

There are three trends I wanted to mention. Despite the fact that we think of most caregivers as women—and in the past nearly 80 percent of them were—there is evidence that this trend is changing. The latest research shows that nearly 4 in 10 family caregivers is a man, and in the workplace there is nearly an even gender split.

This issue is gaining more visibility because employers see greater impact on their bottom line when both male and female come in late, leave early, take leaves of absence or early retirement. Over half of working caregivers of both sexes have to modify their work schedules.

Our recent Sons at Work study indicated that men were as likely as women to report that they were the primary caregiver and that caregiving had negative consequences on their work. Men are much more likely to modify work travel and less likely to speak with either their coworkers or their supervisors. Less than half the men in the study had spoken to their supervisors about their elder care responsibilities. One quote from the study: “Caring for a sick child is an acceptable reason to be taking off. Caring for a sick older relative is not.” In terms of services they would use, more men than women said they would like geriatric care management services, along with help with legal, financial and insurance issues.

Another issue is caregiver health. Caregivers sometimes sacrifice their own health in their focus on the health of their aging relative. Their desire to be a good daughter or a good husband and the stress of juggling the roles of parent, employee, spouse and care-



giver can make them overlook good health care prevention, like immunizations and regular physician check-ups.

The latest data show that one-third of those providing the most intense caregiving—that is personal care for 40 hours a week or more—report their own health as only fair or poor. This is in contrast to 12 percent of caregivers with the least level of burden.

In addition, one-third of these Level 5 caregivers doing the most intense caregiving report that their health has become worse as a result of caregiving. Fifteen percent of caregivers as a whole report caregiving is somewhat or very much a physical strain, and over a third report it is very stressful. We can definitely see the issue of caregiver health becoming a public health issue as the numbers of caregivers grow and the duration of caregiving lasts 4 years and longer.

Finances: Since 1997 we have seen a 30-percent increase in out-of-pocket spending by caregivers, from \$171 a month on home modifications, groceries and other financial support, to \$221 a month in 2003, or \$2,700 a year. We know family caregivers often speak about the financial hardship caregiving can place on a family—decisions they have to make when choosing to help their parents or their kids, sometimes sacrificing vacations, college and other things so they can pay for long-term care. While only 1 in 10 caregivers as a whole says that caring for a family member represents a significant financial hardship, nearly one-quarter of black caregivers do.

Paying for long-term care can be viewed as especially hard because so few people anticipate they will have to pay for it. Most people, baby-boomers and older Americans alike, think that Medicare will cover long-term care expenses, and they also have little idea how expensive it is.

Surveys of America's public perceptions of long-term care costs consistently show people believe they will not need caregiving when they get old, and if they do, it will not cost that much. It is only when families actually face caregiving that they realize the cost in terms of emotional stress, money, and even the toll on their own health.

Thank you.

[The prepared statement of Ms. Hunt follows:]



**Statement by**

**Gail Gibson Hunt  
President and CEO  
National Alliance for Caregiving**

**Before the  
Senate Special Committee on Aging**

**February 10, 2004**



4720 Montgomery Lane, 5<sup>th</sup> Floor  
Bethesda, MD 20814  
[www.caregiving.org](http://www.caregiving.org)



Thank you, Senator Craig, Senator Breaux, and members of the Committee, for the opportunity to provide information on family caregiving. In light of your interest in helping older people stay in the community and to help caregivers in their effort to continue caring for relatives and friends as long as possible, I thought I would focus on some of the newest data on caregiving: who are the family caregivers and what do we know about them? What impact does caregiving have on their lives?

### DEMOGRAPHICS

First, some basic data on family caregivers:

Nearly one-quarter of US households are involved in family caregiving. This number is important because it shows how involved family members are in caring for one another, and how large an issue family caregiving is in our country. It is a myth that Americans abandon their older relatives to nursing homes. Approximately 80 percent of the care for older people is done by family and friends. Peter Arno for the United Hospital Fund has estimated that in the year 2000 the economic value of caregiving to society was \$257 billion per year—larger than the cost of home health care and nursing home care combined!

The profile of the family caregiver is a 46-year-old Baby Boomer woman who is married and works and cares for her 77-year-old mother who lives nearby. The caregiver spends an average of more than 20 hours per week providing care, and caregiving typically lasts more than 4 years.

### THREE TRENDS

Despite the fact that we think of most caregivers as women (and in the past nearly 80 percent of caregivers were women), there is evidence that that trend is changing: the latest research shows that nearly 4 in 10 family caregivers are **men** and, in the workplace, there is a nearly even gender split. This issue is gaining more visibility because employers see a greater impact on their bottom line when both male and female caregivers come in late, take leaves of absence, or take early retirement. Over half of working caregivers of both sexes come in late, leave early, and have to modify their work schedules.

Our recent “Sons At Work” study indicated that men were as likely as women to report that they were the primary caregiver and that caregiving had negative consequences on their work. Men are much more likely to modify work travel and less likely to speak with either their co-workers or their supervisors. Less than half the men in the study had spoken to their supervisors about their eldercare responsibilities. One quote from the study: “Caring for a sick child is an acceptable reason to be taking off; caring for a sick older relative is not.”

In terms of services they would use, more men than women said they would like a geriatric care management service, along with help with legal, financial, and insurance issues.

Another issue is caregiver **health**. Caregivers sometimes sacrifice their own health in their focus on the health of their aging relative. Their desire to be a “good daughter” or a “good husband” and the stress of juggling the roles of parent, employee, spouse AND caregiver can make them



overlook good health care prevention like immunizations and regular physician check-ups. The latest data show that one-third of those providing the most intense caregiving (personal care--bathing, dressing, feeding, transferring--for 40 or more hours per week) report their own health as only fair or poor. This is in contrast to 12 percent of those caregivers with the least level of burden.

In addition, one-third of these Level 5 caregivers doing the most intense caregiving report that their health has become worse as a result of caregiving. Fifteen percent of caregivers as a whole report that caregiving is somewhat or very much a physical strain; and over a third report that it is very stressful.

We can definitely see that the issue of caregiver health is becoming a public health issue as the numbers of caregivers grow and the duration of caregiving lasts an average of four years and longer.

### **FINANCES**

Since 1997 we have seen a 30 percent increase in out-of-pocket spending by caregivers, from \$171 per month on home modifications, groceries, and other financial support to \$221 per month in 2003. We know that family caregivers often speak about the financial hardship that caregiving can place on a family, the decisions that they have to make when choosing to help their parents or their kids—sometimes sacrificing vacations, college, and other things so that they can pay for long-term care. While only one in ten caregivers as a whole says that caring for their family members represents a significant financial hardship, nearly one-quarter of Black caregivers do.

Paying for long-term care can be viewed as especially hard because so few people anticipate that they will have to pay for it. Most people, both Baby Boomers and older Americans alike, think that Medicare will cover long-term care expenses; they also have little idea of how expensive it is. Surveys of the American public's perceptions of long-term care costs consistently show that people believe they will not need caregiving when they grow old and, if they do, it will not cost that much. It is only when families actually face caregiving that they realize the cost in terms of emotional stress, money, and even the toll on their own health.



The CHAIRMAN. Gail, thank you very much for those important observations. I think the spread of knowledge as to the extent of the costs and the commitment of America's families is an important part of the record.

Now, let me turn to Flora Green, better known as Grandma Green.

Ms. GREEN. I deserve it.

The CHAIRMAN. Yes, you do, Flora, and we appreciate that.

She is representing The Seniors Coalition. Welcome to the committee again.

**STATEMENT OF FLORA GREEN, THE SENIORS COALITION,  
WASHINGTON, DC**

Ms. GREEN. Thank you. Mr. Chairman, members of the committee, I am Flora Green, the national spokesperson for The Seniors Coalition. On behalf of our organization's 4 million members and supporters, I would like to thank you for convening this hearing and for your continued work on behalf of American senior citizens, particularly those in need of long-term care services and their families, who donate their home, their time, financial resources to care for them.

I am honored to have been invited to testify this morning and emphasize our support for the passage of the Senior Elder Care Relief and Empowerment, or SECURE, Act, and I wish to thank you for the opportunity to do so.

According to the National Center on Caregiving, 12.1 million Americans require assistance to carry out the very simple, everyday activities that you and I may take for granted. 6.4 million of these Americans are age 65 and over, and nearly two-thirds of these seniors depend upon family members as their only source of help.

Family caregiving is an essential and often overlooked component of long-term care in this country. Approximately 7 million people spend an average of 17.9 hours per week caring for their elderly family members. In addition, the National Alliance for Caregiving reported that over 64 percent of these caregivers have full- or part-time jobs, and many are forced to take decreased hours and unscheduled leave in order to fulfill their responsibility as caregiver.

These individuals sacrifice much in order to provide the noble and compassionate service of caring for their elderly family members, so they deserve our full support. Supporting these caregivers does not mean utilizing more subsidies for institutional care. Today, 79 percent of those seniors who require long-term care services prefer the dignity and security that comes with living in their own homes, with family, or in a community setting rather than being institutionalized.

I recently spoke with Patricia McCarthy Michel, in Florida, who told me her personal story involving her mother who became very ill with Hodgkin's lymphoma in December 2002. She told me that her mother had always been very independent, taking care of all her personal and physical needs, up until this point. By March 2003, it became necessary for her mother to move in with her. Her mother only lived until May 1 of that year. In that short timeframe of less than 2 months, over \$2,000 in expenses were incurred.



These expenses included unreimbursable costs by Medicare/HMO and home health visits that were necessary to assist her.

In addition to Patricia, I also spoke with a Mr. Brown, who is in desperate need of help in caring for his 85-year-old father who has a leg amputated above the knee, a major stroke in 2001 and several heart attacks that left him virtually bed-ridden. Mr. Brown informed me that he is caring for his father 24 hours a day, 7 days a week, bathing him, preparing and administering his medications, feeding him and providing wound care and physical therapy. He made a touching statement. He said this has been a labor of love, but it is becoming a labor. This man needs help.

These are just stories of everyday, humble Americans who are faced with the unavoidable burden of caring for loved ones, a burden which they must add to their regular everyday responsibilities. That the social group to which these individuals belong may include some with limited means simply adds to the problem which this legislation is designed to address.

On behalf of The Seniors Coalition and its 4 million members, I strongly urge you, Mr. Chairman and members of this distinguished committee, to stand in support of the SECURE Act and urge the Senate to move forward with the proposed law.

Thank you so much.

[The prepared statement of Ms. Green follows:]



**US Senate Special Committee on Aging**

**Senior Elder Care Relief and Empowerment (SECURE) Act**

**Testimony of Flora “Grandma” Green  
National Spokesman for The Seniors Coalition  
February 10, 2004**

Mr. Chairman, members of the Committee, I am Flora Green, the National Spokesperson for The Seniors Coalition (TSC). On behalf of our organization and its four million members and supporters, I would like to thank you for convening this hearing and for your continued work on behalf of America’s senior citizens – particularly those in need of Long Term Care services and their families who donate their homes, time, and financial resources to care for them. I am honored to have been invited to testify this morning, and emphasize our support for the passage of the Senior Elder Care Relief and Empowerment, or SECURE, Act; and I wish to thank you for the opportunity to do so.

According to the National Center on Care giving, 12.1 million Americans require assistance to carry out simple, every-day activities that you and I may take for granted. 6.4 million of these Americans are ages 65 and over, and nearly 2/3 of these seniors depend upon family members as their only source of help.



Family care giving is an essential – and often overlooked – component of long term care in this country. Approximately 7 million people spend an average of 17.9 hours per week caring for their elderly family members. In addition, The National Alliance for Care giving reported that over 64 percent of these caregivers have full- or part-time jobs, and many times are forced to take decreased hours, and unscheduled leave in order to fulfill their responsibilities as a caregiver. These individuals sacrifice much in order to provide the noble and compassionate service of caring for their elderly family members, and they deserve our full support.

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These are just but two stories of everyday, humble Americans who are faced with the unavoidable burden of caring for loved ones; a burden which they must add to their regular everyday responsibilities. That the social group to which these individuals belong may include some with limited means simply adds to the problem which this legislation is designed to address.

On behalf of The Seniors Coalition and its 4 million members, I strongly urge you, Mr. Chairman and members of this distinguished Committee, to stand in support of the SECURE Act and urge the Senate to move forward with the proposed law.



The CHAIRMAN. Well, Flora, thank you for that testimony. We are pleased that The Seniors Coalition can endorse the SECURE Act. I think that piece of legislation has some real opportunity. I think it addresses a variety of needs. But as I said in my opening statement, it is one of a lot of pieces that need to come together to fit the different circumstances of situations that people find themselves in out there. Thank you.

Now, let me turn to Richard Teske. Richard is a long-term care expert and former Health and Human Services official.

Richard, thank you for being with us. Please proceed.

#### **STATEMENT OF RICHARD TESKE, WASHINGTON, DC**

Mr. TESKE. Mr. Chairman, it is an honor to be invited to address this committee on family caregiving. I commend the committee for exploring the largest problem facing this country that attracts virtually no public policy attention. For too long, our health programs were run primarily for the providers, payers and the government. Patients came last. It is time for a patients-first approach.

The goal of providing incentives to keep families together is admirable. The use of tax credits to provide incentives for non-institutional long-term care is headed in the right direction. Medicaid is the Federal and State governments' primary long-term care program. But according to Wilbur Cohen, President Johnson's last HEW Secretary, Medicaid's 1965 passage was an after-thought. Inclusion of a nursing home benefit was thought to be a rounding error. Instead, it created an industry. Today, Medicaid covers two-thirds of all nursing home patients and pays half of the Nation's nursing home costs. In the 1980's, home- and community-based waivers were supposed to save nursing home money. Nursing home costs continued to increase, home health costs exploded, and we created another industry.

I would recommend that we learn from these experiences. We need to proceed carefully, lest we again suffer huge unintended consequences. That is why my first recommendation is for you to consider a demonstration project rather than to launch a tax credit program nationwide.

That is also why I applaud President Bush's inclusion in his fiscal year 2005 budget of \$256 million over 5 years for three demonstration projects promoting home care. The budget also proposes \$500 million for a demonstration for current institutionalized patients to return to their communities.

This is the third year that total Medicaid expenditures will exceed Medicare expenditures. This explosion in costs is the primary reason States are facing a fiscal crisis. The recession essentially caused the expansion of Medicaid enrollees from 40 to 50 million in the past 5 years. Most were children and adults who, with economic recovery, hopefully will return to the workforce. However, while less than one percent of the growth is due to the elderly, blind and disabled, they were responsible for 60 percent of the cost increase.

It is imperative that we understand the demographic and services matrix. Adults and children are 72 percent of Medicaid enrollees, but represent only 27 percent of the costs and only 6 percent of home health costs. By contrast, elderly and disabled constitute



27 percent of the enrollees, but two-thirds of all expenditures and a whopping 93 percent of home health care costs.

With the retirement of the baby-boom generation, we can expect a possible quadrupling of long-term care costs in the next 15 years. This would bankrupt every State in the Union. This is why we need to model a non-institutional tax credit so that many people will have the incentive to use their own resources rather than rely on Medicaid for their private long-term care insurance.

I would recommend a higher deductible with a more catastrophic coverage focus. The deductible would be covered possibly by private long-term care insurance or HSAs or maybe Medicaid. But with nursing home costing approximately \$60,000 per year, home health \$50,000 and assisted living \$40,000, we must get this detail right or we will only add to the States' plight.

Should the tax credit be refundable? I don't know, but there is a unique problem to consider. If the goal is to keep families together, most seniors wouldn't qualify for a pure tax credit. This is because a majority of seniors have so little or no income; they pay no income taxes. Perhaps for this group, a refundable tax credit could be considered. In addition, the majority of disabled are under 65. I don't know if your plan intends to eventually include them, but they would be difficult to exclude, given the tax credit's goals.

By using a tax credit rather than the existing entitlement structure, you may introduce consumer choice options. Presently called cash and counseling, Florida, New Jersey and Arkansas has successfully used this to reform the services for disabled enrollees. With the disabled potentially the largest and costliest population, this approach needs to be considered.

Another advantage of the tax credit approach is that it avoids the inequities of the Federal match. In 1995, the Government Accounting Office called the Federal match a complete failure.

Another problem that must be addressed is induced demand. With 80 percent of all care given to people with two or more ADLs receiving the care from unpaid caregivers, this demand will be unleashed. Also, since this care is usually provided by a family member, care shifts from the family to professionals. That may be good, but it should be noted. There is one last but crucial advantage to tax credits. The CMS won't necessarily have to administer it.

I will stop at this point and look forward to your questions. Thank you again for permitting me to address the committee.

[The prepared statement of Mr. Teske follows:]



**SENATE SPECIAL AGING COMMITTEE  
HEARING ON FAMILY CAREGIVING  
10AM  
February 10, 2004**

**628 Dirksen Senate Office Building**

**Statement by  
Richard Teske**

Mr. Chairman and members of the Special Committee on Aging.

It is an honor to be invited to address this Committee on family caregiving. I commend the Committee for exploring the largest problem facing this country that attracts virtually no public policy attention. For too long our health programs were run primarily for providers, payors and the government. Patients came last. It is time for a "Patient's First" approach.

The goal of providing incentives to keep families together is admirable. The use of tax credits to provide incentives for non-institutional Long Term Care (LTC) is headed in the right direction.

Medicaid is the federal and state governments' primary LTC program. According to Wilbur Cohen, President Johnson's last Health, Education and Welfare Secretary, Medicaid's 1965 passage was an afterthought. Inclusion of a nursing home benefit was thought to be a rounding error. Instead it created an industry. Today Medicaid covers 2/3rds of all nursing home patients and pays half of all the nation's nursing home costs.

In the 1980's, Home and Community Based Waivers were supposed to save nursing home money. Nursing home costs continued to increase, home health costs exploded and we created another industry.

I would recommend that we learn from these experiences. We need to proceed carefully lest we again suffer huge unintended consequences. That is why my first recommendation is for you to consider a demonstration project rather than to launch the tax credit program nationwide.

That also is why I applaud President Bush's inclusion in his FY2005 Budget of \$256 million over 5 years for three demonstration projects promoting home care. The budget also proposes \$500 million for a demonstration for current institutionalized patients to return to their communities.



This is the third year that total Medicaid expenditures will exceed Medicare expenditures. This explosion in costs is the primary reason states are facing a fiscal crisis. (This was recognized by Congress when you passed an emergency \$20 Billion plan for the states last year.)

The recession essentially caused the expansion of Medicaid enrollees from 40 to 50 million in the past five years. Most were children and adults who, with economic recovery, hopefully will return to the workforce. However, while less than 1% the growth due is to the elderly, blind and disabled, they were responsible for 60% of the cost increase.

It is imperative that we understand the demographic vs. services matrix. Adults and children are 72% of Medicaid enrollees, but represent only 27.5% of the total costs and only 6.4% of home health costs. By contrast, the elderly and disabled constitute 27% of the enrollees but 66% of all expenditures and a whopping 93.4% of home health care costs.

With the retirement of the baby boom generation, we can expect a possible quadrupling of LTC costs in the next 15 years. This would bankrupt every state in the union. This is why we need to model a non-institutional tax credit so that people will have the incentive to use their own resources rather than rely on Medicaid as a substitute for private LTC insurance.

I would recommend a higher deductible with a more catastrophic coverage focus. The deductible could be covered by private LTC insurance, HSA's or Medicaid. With nursing home care costing approximately \$60,000 per year, home health \$50,000 and assisted living \$40,000, we must get this detail right or we will only add to the states' plight.

Should the tax credit be refundable? I don't know, but there is a unique problem to consider. If the goal is to keep families together, most seniors wouldn't qualify for a pure tax credit. This is because a majority of seniors have so little or no income that they pay no income taxes. Perhaps, for this group, a refundable tax credit could be considered.

In addition, the majority of the disabled are under 65. I don't know if your plan includes them, but they would be difficult to exclude, given the tax credit's goals.

By using a tax credit, rather than the existing entitlement structure, you may introduce consumer choice options. Presently called "Cash and Counseling", Florida, New Jersey and Arkansas have successfully used this to reform the services for the disabled enrollees. With the disabled potentially the largest and costliest population, this approach needs consideration.

Another advantage of a tax credit approach is that it avoids all the inequities of the FMAP, commonly called the "federal match". In 1995, the Government Accounting Office called the FMAP a complete failure. Because any reform would make some states huge winners or losers, comprehensive Medicaid reform has been impossible.



Another problem that must be addressed is induced demand. Eighty per cent of all people with 2 or more ADLs receive their care from unpaid caregivers. With this credit, this demand will be unleashed. Also, since this care is usually provided by a family member, care shifts from the family to professionals. That may be good, but it should be noted.

There is one last but crucial advantage to tax credits: CMS won't necessarily have to administer it.

I would also recommend the Committee explore how this proposal affects Medicare and Medicaid dual eligibles. This is the number one priority problem for the National Governors' Association. Dual eligibles are only 6% of enrollees but 35% of Medicaid's costs.

I will stop at this point and look forward to your questions. Thank you again for permitting me to address the Committee on this important topic.



The CHAIRMAN. You have broadened the perspective of this hearing substantially, Richard. Thank you very much. I think that is provocative testimony.

Trudy, you have obviously expressed the experience you felt or had both with a mother and a sister, and now a father. To what degree would a tax credit have enhanced the support you have already provided? What would that have offered to you and your family?

Ms. ELLIOTT. I think it would have been a true benefit because we had the emotional as well as the financial concern with nowhere to go to get relief. One of the things that I thought was interesting with the comments about Medicaid is that that was a real encouragement from the very beginning when my parents became ill, was to spend down everything they had so that then Medicaid could take care of them, which was a very negative concept for our family. Our family had made a commitment to take care of them, so for us to immediately try to spend down so Medicaid could take care of them was not the mission of our family. So this would be a very positive thing for a family.

The CHAIRMAN. Well, that is so well-spoken. I don't know how many times I have had families tell me just that. They are caught in this phenomenal personal conflict as a result of a need for assistance, and yet at the same time needing, if you will, to spend down resources to cause a qualifying situation to exist.

You obviously with your professional experience assist others in caregiving. Would you say that from what you have seen based on that experience this legislation that we are talking about, a tax credit, would be helpful to a broad cross-section of citizens?

Ms. ELLIOTT. Yes, it definitely would. My story, as I emphasize, is not unique. In my job that I do as far as a director for home care, I hear this so many times throughout the day: What are we going to do? It is definitely a good starting point, and when you said it is multi-faceted, it is a beginning to help families.

One of the family members that contacted me just last week after I was contacted to do the testimony is a primary caregiver for his wife with MS, and he is older and he said, isn't there anywhere I can go to get a tax credit, which I thought was interesting. I had not had anybody ask me that question, so it must be a vital thing.

The CHAIRMAN. Thank you very much.

Sandy, you indicated in your testimony that there is a long waiting list for respite support at the local area agencies on aging. How would extending a tax credit for caregiving reduce the waiting list, or would it?

Ms. MARKWOOD. Well, I think that at this point the area agencies on aging use their National Family Caregiver Support Program monies to be able to provide that respite care. That is where the waiting lists are. If caregivers had some resources on their own, they could supplement by being able to provide some private respite care.

It has just become very clear through this program how important that respite component is. Sometimes, people just need a little relief, a couple of hours a day every once in a while to be able to recharge. As Gail said, the emotional and the health burdens that caregiving impose on caregivers is something that they need relief



from, and respite provides an opportunity. A tax credit would be able to afford caregivers to be able to search out other than public options to be able to get that respite need met.

The CHAIRMAN. Sandy, you heard Richard's statement that action causes reaction, and it does and there is no question about it. If what I am proposing were to become law, it would create new and different dynamics.

Do you agree with Richard in some of what he commented on as it relates to how those dynamics might begin to shape themselves?

Ms. MARKWOOD. I don't see that the National Family Caregiver Support Program has created a new industry of services that is looking to make money on caregivers. What I see is that the programs and the services that have been provided under the National Family Caregiver Support Program have enabled people to do what they want to do, which is to provide care for their loved ones at home.

A tax credit would just be an added benefit to be able to help them do what they want to do already. I don't see it as encouraging people to look for public resources versus using their own private resources. I think the issue becomes oftentimes, as we discussed, the private resources get exhausted. The private resources are stretched too thin. Any financial assistance to be able to help them augment services that they already get or to be able to augment the care they are already providing is just the right thing to do.

The CHAIRMAN. Richard, I used some of your comments in relation to this question. Would you wish to respond at this time on this issue?

Mr. TESKE. Well, we have already heard on this panel testimony about how families spend down and get rid of their assets, and that is a huge problem in the Medicaid program. Only 5 percent of the people have long-term care insurance, but half the people get their long-term care in nursing homes from Medicaid. It is way out of proportion. Basically, the middle class is using Medicaid.

An incentive using a tax credit to keep the middle class in the middle class, not spending down, would be helpful. The present tax laws, however, don't permit that. The incentive is to spend down. There is a whole huge industry of financial advisers in this country that will help you within maybe 3 months to get rid of your assets and go into the nursing home under Medicaid.

Congress passed laws in the early 1990's to go after the financial advisers, make penalties, go after the assets of the senior citizen, the so-called "get granny" laws. One problem is they are never enforced because politically they are poison. So we have to find incentives and this tax credit is a step in that direction for people to remain middle-class, use their assets and encourage them not to drop into the Medicaid program.

The CHAIRMAN. Thank you.

Maybe it was you—yes, it was you, Trudy, who said you had been contacted by a gentleman in relation to assisting his wife and was there a possible tax credit.

I think it goes, Gail, to expanding on your testimony a bit as it relates to the number of men who are now providing care. I see it in working with seniors and the elderly in my State that oftentimes the husband is very quietly taking care of his wife in a relationship



that, as you have said with your parents, was so binding for so long, and is phenomenally burdened by that situation.

Would you elaborate on that new statistic that you are bringing into this discussion? If I were to have been asked the question which group is the larger of the caregivers, I would say, well, it is obviously the woman, and that is what our statistics show and that is where most of our stories, or at least experiences, demonstrate. Could you comment on that?

Ms. HUNT. Well, it is still true that the majority of caregivers are women.

The CHAIRMAN. It is.

Ms. HUNT. That is definitely right; as I said, the profile of the 46-year-old baby-boomer woman. But we are seeing a shift just since 1996 when we did the national caregiver survey. It was 72.5 percent were women, and now 60 percent are women. So we can see there is a significant drop just in that time, a shift.

Part of it is more women in the workplace, so their husbands are sharing in the responsibility of being caregivers. Also, because of divorce, it is really tough to get the wife to take care of the ex-mother-in-law. She is not going to do that.

The CHAIRMAN. More than likely not.

Ms. HUNT. Exactly, exactly. Well, maybe you have to pay her to do it or something. But in any case, we are seeing more men who are taking this on as a responsibility, and I think we need to recognize that because, as I said, in terms of the workplace that begins to have, again, just as with women, a big implication in terms of their taking time off and taking leaves of absence and dropping back to part-time. So it begins to affect both their bottom line as caregivers, but also employers. So perhaps we could begin to address this as we see it being more and more of a genderless issue. We can begin to recognize this and provide more financial support for the caregiver.

The CHAIRMAN. What are the most important challenges for addressing stress-related health problems of family caregivers?

Ms. HUNT. Well, we would suggest that things such as going to see your physician. That is an important issue. There is actually a caregiver self-assessment instrument that the AMA has on its website where if you take this and it looks as if you are suffering from some stress, you should be talking to your physician about this. You should be going to your physician anyway for those regular check-ups and that sort of thing.

There are other programs. Respite is something that helps with stress, as Sandy mentioned; actually, focusing more on being able to take care of yourself, getting exercise, eating right. I think it would be of importance, for example, for the CDC to begin to address this issue as a public health issue and say to caregivers, you need to take care of your own health or you are not going to be around to take care of that wife that you are concerned about or that mother that you are concerned about.

The CHAIRMAN. Thank you very much. I think we all recognize and we all now know so much more about the impact of stress. Obviously, the experience caregivers have can be very stressful because they don't tend, as I have looked at it, to put things aside that they were once doing. They add more to what they are doing



and simply stretch their time out, and stress is usually the product of that kind of enterprise. So thank you so much for your testimony.

Flora, in your testimony you said something that is really at the heart of the SECURE Act, and that is trying to keep people in their own homes or to assist families so that that dignity of the individual staying in their home, if at all possible, is extended.

Would you elaborate on that? In talking with seniors, their greater fear is to lose their home that has been their sanctuary for in many instances most of their lives and to end up in a nursing home. While I have said, and I think we all agree, that there are circumstances and situations where nursing homes fit and are necessary—I don't dispute that, but if you would expand on that feeling that seniors have about those kinds of choices.

Ms. GREEN. This is a very critical issue. In the 3 years that I have spent traveling throughout the United States talking with seniors in the day centers, in the retirement communities, so many say, I wish I were home; I wish there would have been some way that somebody could have gone to the doctor with me. You know, when we lose our ability to drive, we are at the mercy of our family, which doesn't always work out. But there are so many issues like this that folks find to be such a drastic change in life.

I am going to tell you a very personal story about my very own sister, a retired anesthesiologist. She was fortunate enough to have a son living in her home and taking care of her. She suffers from osteoporosis, rheumatoid arthritis and some things she doesn't talk about.

Unfortunately, her son, a Vietnam veteran, shot himself about 8 months ago. Within a week, her family had her into an assisted living community, without giving her the opportunity to make a choice, to decide if there was some way. I hear this over and over: There has to be some way that I can get help to stay in my own apartment, my own home, to take care of myself. My generation are pretty independent.

The CHAIRMAN. Oh, yes, they are. Well, well-spoken, and thank you for your testimony and your advocacy. It is extremely valuable.

Richard, your testimony opened with a reference to a patient-first approach. Would you elaborate on that?

Mr. TESKE. Certainly. Most of our health care programs are designed to control costs, not necessarily provide quality care. Just an anecdote: When I was at HCFA many years ago, we had three policy bureaus. One was called Coverage, one was called Eligibility, and one was called Reimbursement. There wasn't a quality bureau. The people there get bonuses based on the money they save, not the quality of care they give. So the entire structure is not modeled to provide incentives for quality care.

In the Medicaid program, you are assigned a provider; you don't choose your provider, like in the middle class. In fact, you don't even have a single physician watching out for your continuity of care. Companies go in and out of the program. You get a new physician each time another company takes over the plan.

This is especially harmful in the rural areas and in the urban areas. Only a few years ago, half the physicians were taking Medicaid patients; now, only 37 percent. They are dropping out of the



program. So there are a number of things within the actual structure of our programs that don't really help the patient. It is there to help the provider save money for the government or save some money for the payors.

The CHAIRMAN. Well, we hope that this reform package we have put in place begins to go at some of that.

Mr. TESKE. Absolutely.

The CHAIRMAN. I think it will, especially that urban/rural differential problem that we have clearly experienced in the rural States. Hopefully, that has been substantially corrected in the provider area, and it will offer some flexibility, I think, to the consumer.

The Medicaid program is a State-Federal partnership, as you have spoken to. Demand for long-term care is certain to increase in the next decade, and State leaders are increasingly aware of that trend. It was true in my State of Idaho this past year. But it was not untypical of other States that had budget shortfalls. One of the greatest struggles was trying to deal with the matching money and the services offered through Medicaid and how that got done or where do we cut, because that is obviously part of a decisionmaking process with funding.

Are States using tax credit relief to help address this trend?

Mr. TESKE. Yes, they are. I think it is something like 22 States are using a tax credit or a tax deduction to help in this area, and this might be the route you wish to take. In my testimony I recommended a demonstration project rather than going nationwide, but maybe looking at these individual States and how they administer these credits could be very useful.

For example, the services covered as non-institutional long-term care could be different. Is it a credit or a tax deduction? Is it a refundable credit or a regular credit? At what level of the Federal poverty level or income level, or is there no income application involved? Is the total benefit capped or uncapped, and the number of ADLs you have to have before the credit clicks in?

All these things are probably different in all of these States and they will provide different incentives for different types of behavior. I would suggest that the committee take a look at these different State credits and deductions and see how they operate and see how broad or narrow they are, et cetera. It might be very helpful.

The CHAIRMAN. I think that is excellent advice. We will see what we can do in that area.

You talked about the Federal medical assistance percentage or Federal match to Medicaid. Can you describe what this is and how it works?

Mr. TESKE. It is a complicated formula that is calculated based on the State's per-capita income. The Federal Government will match a certain percentage of expenditures that the State makes for Medicaid. In the rich States, it is a 50-50 match, like in New York. New York will spend, let's say, I think it is close to \$10,000 now per capita. The Federal Government will match it at a 50-50 rate. They will get \$5,000 from the Federal Government to match their \$5,000.

It goes up as high at times as an 83/17-percent match. In Mississippi, a few years ago it was 83-17. It was calculated that way



so the poorer States wouldn't be hurt and that the Federal Government would provide additional revenue.

But the problem is, given the different qualification and eligibility and benefit packages between the States, what has happened is that New York, even though it is at a 50–50 match, spends almost three times the amount per capita as Mississippi does. That inequity is built into the structure again, and any attempt to change that obviously New York's congressional delegation wouldn't be too happy with. Let's put it this way. The inequities in the Federal match has frozen structural reform in the Medicaid program for almost 40 years.

The CHAIRMAN. I appreciate that observation. I have experienced that debate and/or discussion on the floor of the Senate more than once.

How might a tax credit approach similar to my proposal help address Medicaid spending pressures?

Mr. TESKE. Well, as I say, the big pressure right now in the long term is the problem of long-term care. Right now, as my testimony said, we have the problems of the recession putting a burden on the Medicaid program, and that is the No. 1 issue for the National Governors Association saying that it is driving the States into fiscal crisis. The Congress recognized this with their \$20 billion special appropriation last year.

I would just point to the people on this panel and their testimony. It is almost universal that people want to stay in their homes, and they would prefer not to be on Medicaid. Anything that we can do to provide those kinds of incentives obviously would take the burden off the Medicaid program.

I think the tax credit idea, which, as modeled, is probably targeted more to the middle class right now, would indeed address that problem. It would probably not change the percentages too much between the States, but it would obviously have a large impact on their long-term care costs.

The CHAIRMAN. Thank you.

Before we conclude, let me turn to the whole panel. Is there anything left to be said?

Yes, Flora.

Ms. GREEN. As I am listening, I am thinking about the—let me give you a case in point, a single woman maybe with a couple of children who lives in an apartment. Her only source of income is, let's say, \$1,200 a month Social Security. She is over the cap on Medicaid. She doesn't have enough money to continue her medical care. It is a real problem.

This is the kind of situation that needs to be addressed because there is a big gap there. Again, the pride issue comes into effect. They have more money; well, at least someone thinks they have more money, so they are not eligible for any kind of help within the State welfare program. So they float around, hoping from day to day. This is really true that they are going to survive until the 3rd of next month.

The CHAIRMAN. I am sure it is, because they are right on the margin in many instances.

Is there anything else that any one of you would like to say about this issue?



Yes, Gail.

Ms. HUNT. I would just like to say I think this bill that you are proposing is really positive in that it is looking for the first time to give support to middle-class people who are doing caregiving. There have been programs that have dealt to some extent with the lower-income people, but I hear all the time from people who are middle class or sort of somewhat above the poverty level saying isn't there something out there, isn't there some way that I could get some financial support to help me take care of my parents who are living at home? I would like to be able to keep them nearby. There is really nothing out there, so this is a good step.

The CHAIRMAN. It is also directed right at that spouse who ends up being the caregiver of the spouse, and baby-boomers. But more importantly at this moment, in that other age group that my parents fall into and others. They thought they had planned well. They thought they had a lot of money for retirement. They find out they didn't and so they keep tightening down, tightening down. They are very conservative folks to begin with. They spend less and less so they can take care of themselves. Then something like this hits that really is beyond—and I think most of you have expressed that—their ability, or it is an unanticipated expense beyond their resources.

All of a sudden, that well-planned retirement disappears, and that is part of what we are looking at here. There is no question, it is looking at the middle class who has a resource. But it is a resource that can be rapidly depleted with the cost of health care today, simply because they had not acquired that long-term health care insurance or it wasn't available at a time when it might have been more affordable for them. This hopes to fill that hole a bit.

Ms. HUNT. I just wanted to also mention the thing to keep in mind is you can get baby-boomers of today and encourage them to purchase long-term care insurance. Older people typically can't buy long-term care insurance.

The CHAIRMAN. That is right.

Ms. HUNT. They maybe can't be underwritten. They have diabetes or whatever the illness is, or it is just not affordable if they are in their 70's or so. So this is really something to help people for today.

The CHAIRMAN. Well, that is very true. I think that clearly long-term health care insurance is becoming and will continue to become a very attractive package for well-planned-out baby-boomers, if you will, and younger who are looking at their retirement years and looking at being self-sufficient and being able to sustain their lifestyles without family and/or Federal assistance.

Any other comments? Yes, Richard.

Mr. TESKE. I just thought of another salutary effect of this approach vis-a-vis the States. One of the thorniest problems existing is the problem of so-called dual Medicare and Medicaid eligibles—6 percent of the enrollees, 35 percent of the total costs.

As any Governor can tell you, this issue is so complex, that whole area, that this tax credit again provides an incentive for those people not to go into the Medicaid program and become a dual-eligible, but get the services outside.



The CHAIRMAN. That is a fascinating observation. I mean, I have struggled with the definition of and those funding problems with dual eligibility. I had not thought of it in that context.

Yes, Sandy.

Ms. MARKWOOD. Senator Craig, playing on what Gail had mentioned, I think this is a wonderful—the tax credit is a wonderful benefit for individuals. I think it goes into the context of making sure that people have the discussions with their families on planning for old age, planning for long-term care needs, and this would be a wonderful tool to help people in that regard.

For the generation who is 65-plus now, as you said, they thought they had planned for their retirement, they thought they had saved, and then because of the cost of health care found out that they haven't. There is a whole generation of baby-boomers who, we are fearful, are not planning for their retirement years and their long-term care years.

This tax credit is something that can help them as educational materials go out to help them think of how this fits into the overall context of their plans for their latter years. I think that there needs to be a broader discussion in this country about planning for old age.

The CHAIRMAN. Well, that is very well-said. In fact, it is so well-said that we will let that be the last word. Thank you all very much for your time this morning. We will stay in touch with all of you as we work this issue and develop a support base for it, but I do believe it is an issue whose time is here and we are going to enlist the Senate and the House to become very active in support of it.

Thank you all. The committee will stand adjourned.

[Whereupon, at 11:11 a.m., the committee was adjourned.]







## A P P E N D I X

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### PREPARED STATEMENT OF SENATOR GORDON SMITH

Thank you, Mr. Chairman, for holding a hearing on this important issue. Caring for a loved one in the home can be expensive and trying for everyone involved. Family members often have to quit their jobs to care for a family member. Tremendous resources are drained by families in order to pay for in-home service providers.

Often, due to the high expense of care and dwindling resources, seniors are pushed into the Medicaid system. According to the National Family Caregiver Association, more than 335,000 Oregonians serve as caregivers. In dollar terms, this translates to 360 million caregiver hours per year, with a market value of \$3.2 billion.

Nationally, more than 22 million families in this country have caregiver responsibilities of some kind or another. According to a recent American Medical Association article, 80 percent of home care services are provided by caregivers, and the aggregate value of their services exceeds \$200 billion per year. In addition, the estimated annual impact of caregiving on American business—in terms of lost days, reduced productivity—is \$29 billion.

Clearly, this is an issue that is only going to grow in importance as the greying of America progresses. One thing we in Congress can do is support legislation that uses the tax code to help family caregivers. I am a cosponsor of Senator Grassley's Long Term Care and Retirement Security Act, and I am eager to learn more about Senator Craig's Senior Eldercare Relief and Empowerment Act.

On a related topic, I am also a supporter of Senator Breaux's Elder Justice Act, which recognizes that seniors encounter many abuse, neglect, exploitation. Passing this bill would provide resources for programs to train caregivers on how to avoid elder abuse, and I hope the Senate will address both these bills before the end of the year. Our seniors deserve nothing less.

